



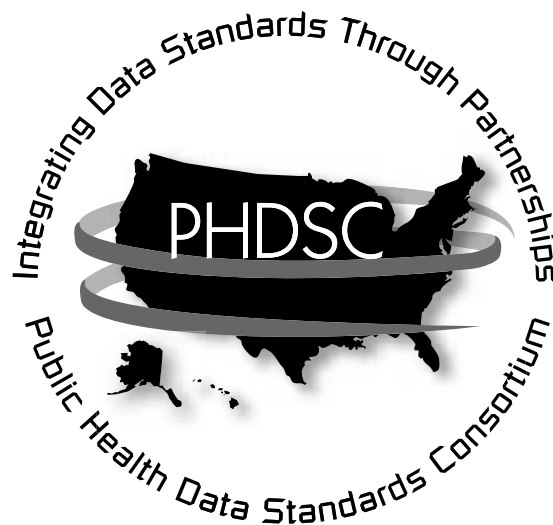
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Public Health Data Standards Consortium



DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention • National Center for Health Statistics

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Public Health Data Standards Consortium

Background

The public health and health services research communities need to have a voice at the table in the development of national health data standards. This is the driving force behind the Public Health Data Standards Consortium (PHDSC). The Consortium was established in response to recommendations from a 1998 workshop that explored the implications of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Administrative Simplification Provisions for the practice of public health and health services research. These provisions direct the Secretary of Health and Human Services to adopt a variety of administrative and financial health care standards. They also encourage standardization of electronic patient medical records and provide an impetus for more comparable and secure data across the spectrum of health and health care.

Participants at the HIPAA Workshop developed consensus recommendations for establishing a Consortium to organize the public health and the health services research communities on data standards issues. This Consortium, established in January 1999, serves as a mechanism for ongoing representation of public health and health services research interests in data standards setting processes including HIPAA implementation.

What Is the Consortium?

The Consortium is a coalition of organizations committed to the promotion of data standards for public health and health services research through the collaboration of State, Federal, and private sector organizations. This involves using existing voluntary standards established by the standards development organizations (for example, American National Standards Institute-Accredited Standards Committee (ANSI ASC) X12 and Health Level 7), where applicable, and encouraging participation in the standards process where current standards do not meet public health needs.

The Consortium has adopted the definition of public health in the United States as developed by the Public Health Functions Steering Committee in

1994. The public health vision, as exemplified in the objectives of the Healthy People 2010 initiative, is healthy people in healthy communities, and the mission is to promote physical and mental health and prevent disease, injury, and disability.

Public health prevents epidemics and the spread of disease, protects against environmental hazards, prevents injuries, promotes and encourages healthy behaviors, responds to disasters and assists communities in recovery, and assures the quality and accessibility of health services. Health services research supports the functions of public health through data gathering, research and information exchange on the delivery, quality, and financing of the health care system.

The Consortium is committed to comprehensive, integrated, and coordinated health data standards that are clinically sound as well as culturally relevant and consumer- and family-friendly. Thus, decisions about standards will consider the needs of a community-based as well as a population-based approach.

The Consortium is not an advisory body to the Department of Health and Human Services or any other governmental agencies regarding data standardization issues. The individual member organizations, groups of member organizations, or the Consortium may provide advice or recommendations to the National Committee on Vital and Health Statistics, which is the advisory committee to the Department of Health and Human Services on health information policy.

Mission

The mission of the PHDSC is to improve the health and health care of the U.S. population through improved health related information by expanding involvement in existing health data standards and content organizations. The Consortium determines standards needs through consultation with stakeholders, facilitates the use of existing national standards and identifies priorities for the development of new national data standards for public health and health services research. The Consortium works with its members and other partners to educate the public health and the health services research communities about health data standards issues.

Goals and Strategies

- Improve the health and health care of the U.S. population through improved health related information.
- Convene local, State, and national health services researchers and public health practitioners around data standards issues, utilizing existing organizations to facilitate communication with and disseminate information to other stakeholders.
- Identify high priority data needs that can be met through the HIPAA transaction and clinical standards, as well as other standards setting processes (for example, American National Standards Institute-Accredited Standards Committee (ANSI ASC) X12 and Health Level 7 (HL7)).

- Encourage participation and seek formal representation on data content committees (for example, National Uniform Billing Committee and National Uniform Claim Committee).
- Educate public health practitioners, health services researchers, and other stakeholders about standards issues, working through member organizations as appropriate.
- Promote Consortium efforts and relevant efforts of other data organizations and committees to help ensure continued access to health care information by public health practitioners and by health services researchers, with the appropriate safeguards for confidentiality of individually identifiable data.

Accomplishments

The Consortium held its first meeting on January 24–25, 1999, in conjunction with the annual meeting of the National Association of Health Data Organizations (NAHDO).

Many important activities have taken place in the short history of the Consortium. The accomplishments and milestones in identifying and representing the needs of public health and research include:

- In 1999 the National Uniform Billing Committee and National Uniform Claim Committee both approved Federal and State Consortium representation on their respective committees.
- In September 1999 the National Center for Health Statistics awarded a contract to NAHDO to identify and characterize public health and research data needs for State encounter data.
- On December 7, 1999, an educational teleconference addressing HIPAA and data standards was sponsored by NCHS and facilitated by NAHDO. The teleconference was an overwhelming success with more than 100 participants.
- The Consortium Steering Committee held its first meeting on March 21, 2000:
 - The results of the NAHDO study were discussed, the data needs were prioritized, and a work plan was developed.
 - Operating principles were developed to solidify the Consortium's organizational structure and to govern Consortium activities.
 - A standing Education Work Group was established to develop and implement an educational strategy.
 - Ad Hoc Work Groups were established on External Cause of Injury Codes (E-Codes), Mother's Medical Record Number, and Payer Type to assist in further exploring the need to include these high priority data elements in the national HIPAA Standards and Implementation Guides.
- The Consortium organizes representation at the trimester meetings of the Standards Development Organizations (ANSI ASC X12 and HL7):

- The Consortium reports on activities at HL7 through the Government Special Interest Group.
- The first Public Health Caucus was held at ANSI ASC X12 on June 5, 2000.
- The Consortium participates in the standards development process:
 - At the February 2000 trimester meeting of ANSI ASC X12, the Claim/Encounter Work Group approved the Department of Health and Human Services request to change the next version of the 837 Institutional Guide to allow the collection of race/ethnicity on the claim. The business case was developed by the Consortium, which had identified the value of this information to the numerous States that collect it.
 - At the June 2000 trimester meeting of ANSI ASC X12, the Consortium succeeded in its request for the data element, mother's medical record number, to be added to the ANSI ASC X12 standard. This allows for a linkage in hospital discharge records between the mother's record and her newborn: this linkage will promote the identification of risk factors in determining current and future treatment needs for newborns by public health practitioners and health services researchers.
 - At the February 2001 trimester meeting of ANSI ASC X12, the Consortium received approval to develop a Health Care Service Data Reporting Implementation Guide. The guide will provide the framework for promoting the migration of public health encounter data systems to national data standards by using the framework of the 837 Institutional Standard. It will also promote high quality reporting of elements included in the 837 standard that are important to public health, such as External Cause of Injury Codes, Race and Ethnicity, Mother's Medical Record Number, and Diagnosis Indicator.
 - During the spring of 2001 the Consortium organized to respond to the Designated Standards Maintenance Organizations' (DSMO) review of the change requests to the HIPAA transaction standards. A formal letter was submitted to the National Committee on Vital and Health Statistics to express concerns regarding removal of specific data elements from the standards. Consortium representatives participated in the review process and submitted business cases to the X12 Work Group. The newborn birth weight was successfully preserved as part of the institutional claim.
- The Consortium held the second Annual Public Health Data Standards Consortium Steering Committee meeting in March 2001.
- The preliminary recommendations in the Education Strategy were discussed and prioritized. The highest priorities identified include:
 - Strengthen educational partnerships for collaboration in supporting data standardization.

- Coordinate educational activities with the National Electronic Disease Surveillance System (NEDSS) to enhance the effectiveness of the CDC voice in promoting standards that meet the full array of public health needs.
- Secure funding to carry out the mission of the Education Strategy.
- Develop and disseminate educational messages to public health, health services research communities, and the public in the implementation of HIPAA Administrative Simplification and other data standards setting processes.
- Develop a Web-based resource center to track and provide educational resources on data standardization and standards implementation efforts relevant to public health including HIPAA standards and other relevant standards efforts.
- Create a Health Care Service Data Reporting Guide to migrate State encounter data systems to national standards.
- Several new work groups were identified including: Securing Funding, Web-based Resource Center, Overcoming Barriers/Strategic Planning, and Health Care Service Data Reporting Guide.

Membership

Consortium membership is open to any organization with a public health focus and with an interest in data standardization for the purposes of health services research and public health practice. These members may include any organization that collects, generates, or uses public health data to improve the physical and mental health of a population.

Member organizations currently include:

Academy for Health Services Research and Health Policy (AHSRHP)
 Agency for Healthcare Research and Quality (AHRQ)
 Association of Maternal and Child Health Programs (AMCHP)
 Association of Public Health Laboratories (APHL)
 Association of State and Territorial Health Officials (ASTHO)
 California Cancer Registry (CCR)
 California Office of Statewide Health Planning and Development (OSHPD)
 Centers for Disease Control and Prevention (CDC)
 CDC/National Center for Health Statistics (NCHS)
 Council of State and Territorial Epidemiologists (CSTE)
 Health Care Financing Administration/Medicaid (HCFA)
 Health Care Financing Administration/Medicare (HCFA)
 Health Resources and Services Administration (HRSA)
 Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
 Massachusetts Division of Healthcare Finance and Policy
 Massachusetts Health Data Consortium (MHDC)
 Mental Health Statistics Improvement Program (MHSIP)
 Minnesota Health Data Institute (MHDI)
 National Academy for State Health Policy (NASHP)

National Association of County and City Health Officials (NACCHO)
 National Association of Health Data Organizations (NAHDO)
 National Association of Local Boards of Health (NALBOH)
 National Association of Public Health Statistics and Information Systems
 (NAPHSIS)
 National Association of State Alcohol and Drug Abuse Directors (NASADAD)
 Nebraska Health and Human Services System
 New York Statewide Planning and Research Cooperative System (SPARCS)
 Public Health Foundation (PHF)
 State and Territorial Injury Prevention Directors Association (STIPDA)
 Substance Abuse and Mental Health Services Administration
 (SAMHSA)/Center for Mental Health Services (CMHS)
 Washington State Department of Health
 Wisconsin Bureau of Health Information
 Work Group for the Computerization of Behavioral Health and Human
 Services Records

Organizational Structure

The organizational structure of the Consortium consists of a Steering Committee, Planning Group, Standing Work Groups and Ad Hoc Work Groups.

Steering Committee

The Steering Committee includes one principal representative and alternate representative from each member organization to facilitate the following roles and responsibilities for their respective organization:

- Designate Consortium Steering Committee principal and alternate member.
- Participate in all Consortium meetings and conference calls.
- Disseminate information regarding Consortium activities to its members and/or public health practitioner clients, and all public and private sector stakeholders (including consumers, families, and consumer advocates) affected by Consortium recommendations.
- Solicit feedback from its members on any Consortium business and necessary issues.
- Promote the activities of the Consortium at any of its meetings as feasible.
- Subscribe to the Consortium listserv and participate in listserv discussions regarding issues of data standardization for health services research and public health.
- Participate in discussions and decisionmaking regarding Consortium workplan and projects and be involved in Consortium activities as able and as necessary.

- Represent Consortium proposals at the appropriate data standards development organization or data content committee.
- Identify and obtain support from other members of their organization to work on Consortium projects, work groups, and other relevant groups.

Planning Group

The Planning Group for the Consortium consists of up to 10 individuals selected annually by the Steering Committee and includes the Federal and State representatives of the Consortium to the National Uniform Billing Committee and the National Uniform Claim Committee. This group performs the administrative functions of the Consortium such as: scheduling and planning meetings, seeking out and ensuring budgetary resources, keeping Consortium records including all meeting minutes, and maintaining the Consortium Web site and listserv.

Standing Work Groups

The Standing Work Groups are established by the Consortium Steering Committee to be responsible for projects that address on-going and dynamic issues in data standardization. Any member of a Consortium member organization with an interest in, and some knowledge of, the subject matter can serve as either member or chair of a Standing Work Group. Standing Work Groups are permanent entities of the Consortium until otherwise determined by the Steering Committee, and report directly to the Steering Committee.

Education Work Group

The Education Work Group was developed to collaborate with other work groups and oversee the implementation of the Consortium's education strategy to promote data standardization issues relevant to HIPAA and other health data standardization processes. The Education Work Group addresses such topics as education, communication, public relations, HIPAA implementation, technical assistance, and user-friendly data dictionaries. The Education Work Group also supports education on other public health data standards efforts, including NEDSS implementation. This work group is considered a Standing Work Group as a result of their involvement in on-going and dynamic issues in education for data standardization.

The Education Work Group cochairs are:

Robert Davis, M.S.
Director
SPARCS, New York Department of Health

Walter Suarez, M.D., M.P.H.
Executive Director
Minnesota Health Data Institute (MHDI)

The Work Group contracted with The Lewin Group, Inc., in collaboration with the National Association of Health Data Organizations (NAHDO) to develop an education strategy to guide the initial efforts of the work group. The education strategy identified the role of the Consortium in three phases: building partnerships and educating constituencies, participation in the development of national standards, and support for standards implementation for public health and health services research.

Ad Hoc Work Groups

Ad Hoc Work Groups were created to assume responsibility for coordination and implementation of any project approved by the Consortium Steering Committee. Any member of a Consortium member organization can serve as either member or chair of an ad hoc work group. An Ad Hoc Work Group will cease to exist when its work has been completed and it has submitted a final report to the Consortium Steering Committee. The established Ad Hoc Work Groups include the External Cause of Injury (E-Codes) and the Payer Type Work Group. The proposed Ad Hoc Work Groups include the Readmission and Individual Identifier, Source of Admission and Functional Status Work Groups.

External Cause-of-Injury (E-Codes) Work Group

The External Cause-of-Injury (E-Codes) Work Group was originally formed to develop justification and recommendations for expanding the collection of External Cause-of-Injury codes in the 837 Institutional Health Care Claim.

The E-Codes Work Group cochairs are:

J. Arturo Coto, M.D., M.P.H.
Disease Surveillance Coordinator
Nebraska Health & Human Services System

Andye Zach, R.H.I.A., M.P.A.
Acting Deputy Director
California Office of Statewide Health Planning and Development

The charge of the E-Codes Work Group is to evaluate the current practice in E-code collection and to assess and propose the next steps necessary to improve E-code reporting in discharge data systems and electronic reporting standards. The Work Group has reviewed the pros and cons of E-code reporting, States' current practice of E-code reporting and reports of other organizations' recommendations regarding collection of external cause of injury data. The E-Codes Work Group plans to finalize a business case to include justification for designated fields for place of occurrence and additional E-codes. The Work Group also plans to develop an E-codes education strategy.

Payer Type Work Group

The Payer Type Work Group develops justification and recommendations for a standardized classification of payer type that can be used by public health and health services research.

The Payer Type Work Group cochairs are:

Amy Bernstein, ScD
Director, Development and Analysis Group
Centers for Disease Control and Prevention (CDC)
National Center for Health Statistics (NCHS)

Susan Elder, M.A.
Director, Health Statistics
Missouri Department of Health
Center for Health Information Management and Evaluation

The Payer Type Work Group determined that the existing X12N categories in the subscriber section of the 837 Institutional claim are currently neither mutually exclusive nor comprehensive, in part because they were not created for research purposes. Regardless of the eventual X12N status, some states have indicated that they would welcome a standardized Payer Type typology that would enable them to compare data by payment category to data from other states, to other data collection initiatives, and across different types of providers. The Work Group has proposed a typology with broad payer categories and subcategories for reporting and analyzing payer data for public health and health services. The Work Group is currently refining and expanding the development of the payer type typology.

Communication

Listserv

As a medium for information dissemination and for the discussion of data standards issues, the Consortium has established a listserv called the PH-CONSORTIUM-L. Subscription to this listserv is not restricted to member organizations but is open to anyone who wishes to participate.

To subscribe to the PH-CONSORTIUM-L listserv via your e-mail:

- Send e-mail to LISTSERVLIST.NIH.GOV with the following text in the message body:

SUBSCRIBE PH-CONSORTIUM-L YOUR NAME

To send mail to the listserv via your e-mail:

- Address your e-mail message to:

PH-CONSORTIUM-LLIST.NIH.GOV

To send mail to an individual address your message to that individual's e-mail address.

**You may also access the listserv via the WEB at <http://list.nih.gov>
The advantage is you can subscribe and post messages to the
listserv using different e-mail addresses and different Web browsers.**

- At the Home page, click on Browse and follow the steps to access the PH-CONSORTIUM-L list (click on the search button "P").
- This allows you to SUBSCRIBE, UNSUBSCRIBE, POST MESSAGES and VIEW ARCHIVES
- You can use any e-mail address as long as you create a password for that address. You may use the same password for multiple addresses if you wish. If you have already subscribed, you may use that same e-mail address and password or you can subscribe again with a different one. Listserv associates your address with your password.
- For security reasons, an E-mail will be sent to the address indicated within a moment, requiring you to confirm your request. Bring up your e-mail to access this request for confirmation.
- To confirm, either click on the web link indicated or press the reply button on your e-mail and type the word OK in the body of the reply.
- After confirming your password, return to the listserv login screen on your browser and proceed.

Please contact one of the listserv owners for problems or questions:

Suzie Burke-Bebbee
(301) 458-4125
E-mail: zxj6@cdc.gov

Michelle Williamson
(301) 458-4618
E-mail: zup9@cdc.gov

Web Site

The Web site for the Centers for Disease Control and Prevention, National Center for Health Statistics is the home for the Public Health Data Standards Consortium's Web site. The Web site has detailed information about the Consortium and the various work groups. The site offers several links to national, Federal, State, and regional organizations related to data standards.

The URL for the Web site is www.cdc.gov/nchs/otheract/phdsc/phdsc.htm.

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